

Preface

Led by Co-Chairs Mike Gilliam, Jr. and Patricia Gail Bray, PhD, members of the Workgroup¹ collaborated extensively through telephone conference calls, email and in meetings at the Texas Department of Health (TDH) in Austin. This collaboration, guided by a plan for work that defined timelines and deliverables, was cordial and constructive. This Final Report, a consensus document, reflects contributions from each member of the Workgroup and includes the definition of the problem, recommendations and the following policy statement:

Data-Driven Health Policy Saves Resources and Improves the Lives of Texans.

FINAL REPORT: Workgroup L

I. Executive Summary

In 2002 the Texas Department of Health (TDH) convened partners in Texas' public health system to identify shared priorities and actions for improving the health of Texans. Texas State Strategic Health Partnership is made up of public and private organizations that have come together to share responsibility and accountability for creating a healthier Texas. The Partnership has created twelve goals to ensure the success of this vision of improving the health of Texans. The twelfth goal, "L" is described below: By 2010, the Texas public health system partners will be informed by, and make decisions based on, a statewide, real-time, standardized, integrated data

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collection and reporting system(s) for demographic, morbidity, mortality, and behavioral health indicators accessible at the local level which also protects the privacy of Texans.

Members of Workgroup L have conducted research to confirm in Texas what specialists from the National Committee on Vital and Health Statistics, the Centers for Disease Control and Prevention's National Center for Health Statistics, and the Data Council of the U.S. Department of Health and Human Services (2002) have found nationally, that is, improvements in the health of populations will be increasingly dependent upon progress in the development and deployment of computerized systems that can provide timely access to policy-relevant information.

In Texas, as elsewhere, information systems tend to exist as isolated silos and, as such, reflect a more narrow view of population health and of the factors that influence health than would otherwise be appropriate. Getting from silo to silo without connecting walkways can be daunting. In order to address the complexities and dynamics of the factors that impact community life, for example, it is necessary to pull together facts assimilated from data that are collected by a variety of agencies and organizations, for a variety of purposes, and are maintained and reported in formats that lack consistency and standardization. The potential usefulness of these records is limited by this variability in basic structure, geographic scope, and definitions of key terms. Transforming "data" into meaningful information through appropriate interpretation and dissemination, never an automatic or inexpensive process, is particularly difficult in these circumstances. Because existing systems are segregated by political jurisdiction and by agency divisions, communications and data exchanges among them are problematic. In practical terms, this means that searches from database to database for answers to relatively simple and straightforward questions often lead nowhere.

As members of the public increasingly expect and, after September 11, as governments increasingly demand, it should be possible to answer pertinent questions with information that is accurate, detailed, relevant and complete. The technology to deliver these answers is available and relatively inexpensive. It is becoming

increasingly difficult to defend the old ways of doing. To an upcoming generation of stakeholders for whom the word “Google” is a verb, shortcomings in existing health information arrangements that earlier might have been tolerated as merely inconvenient are likely to be seen in the future as frankly intolerable.

In this Final Report, members of Workgroup L describe the underlying problem, and set out recommendations for policies and actions that will mitigate the most severe aspects of the problem. Texas has made heartening progress in upgrading the capabilities of its data collection and reporting systems. This Report recommends that momentum in that positive direction be maintained.

II. Dimensions of the problem

Clear from findings in the landmark *Health of Texans 2002* is a clarion call for data that are “...current, accurate, comparable over time and location, and easily accessible.”

Unfortunately, as the findings noted, “For some important diseases and health conditions in Texas, the data do not meet these criteria” (Health of Texans, 2002, p. X).

There are compelling reasons for concern about inadequacies in record keeping and reporting arrangements in the state. Information is often said to be the foundation upon which public health and health policy have been built. While a wide array of data resources in Texas deals with the health of populations, TDH shoulders primary responsibilities for data collection and reporting in this area. TDH operations have been examined closely in three recent reports.

The first, the *Business Practices Evaluation* prepared by consultant Elton Bomer in August, 2001, recommended improving public access to agency information. Specifically, the Bomer report recommended creating a “Center for Health Statistics.” The report urged:

The new Center for Health Statistics should be formed utilizing existing resources at TDH. Its core structure would be the current Policy and Planning Division minus the Strategic Planning function, and it would be augmented by other resources currently residing in the programs. It should report directly to the Deputy Commissioner for Administration to most easily coordinate with the Associateship for Information Systems. The Center would provide a single place for external customers to inquire about many state health datasets. It should also allow the agency, through analysis of key health data and indicators, to spot trends and potential problems and work with local health officials on coordinated provision of information to the public and on rapid response to identified issues (Bomer 2001, p. 54).

The second report, provided by the Sunset Advisory Commission in its *Special Purpose Review* (November, 2002), cited TDH's challenges in providing accurate and timely information. The Sunset Advisory Commission (2002, p. 15) recommended that TDH:

- Create "a central toll-free number for easier public access to information and assistance"
- Revise media communications policies
- Employ a correspondence tracking system
- Create a Web site portal linking to all TDH databases and serving as a central, online repository of information.

The third report, the *Blueprint* (Appendix D, Fiscal Years, 2001 – 2002) focused on the need for an Integrated Public Health Information and Surveillance System, and specifically recommended the following:

TDH will have a data collection and management system that provides the information necessary to support effective leadership in assessing and improving the health of Texans, to assist communities in assessing their health needs and in determining solutions to identified problems, and to measure the effectiveness of interventions....TDH should improve the availability and accessibility of community-based information for use by TDH programs and by TDH customers through the development of integrated databases to report on standard health indicators, and the development of a web-based query system to access data, while maintaining confidentiality safeguards to protect the privacy of individuals (Blueprint, p. 220).

In a relatively short period of time, TDH has made encouraging, incremental progress in adopting these recommendations and in implementing the suggested reforms. More effectiveness in efforts at saving lives and saving money, however, will require further improvement in current data collection and reporting systems and in coordination among systems maintained by other agencies and organizations.

The partners of the public health system constitute a complex network of public, private, state, local, academic, volunteer, and service-delivery entities with numerous and widely varied functions that are reflected in disparate arrangements for keeping records and for reporting. These entities form multiple and interrelated, but independently operating, systems. Each of these systems employs specific public health methods to prevent different health threats from adversely affecting the population; taken together they are distinguished by a lack of integration and coordination.

Traditionally, public health systems collect data on mortality and morbidity (through surveillance methods such as disease or injury registries and infectious disease reporting systems) with enough precision to know which subpopulations are at greatest risk for certain diseases. The data are used mainly to understand the magnitude of health problems in populations and to help identify appropriate responses. Good information can lead to good outcomes in detecting acute disease outbreaks, in monitoring changes in infectious agents, in evaluating public health research, and in clarifying the natural history of diseases.

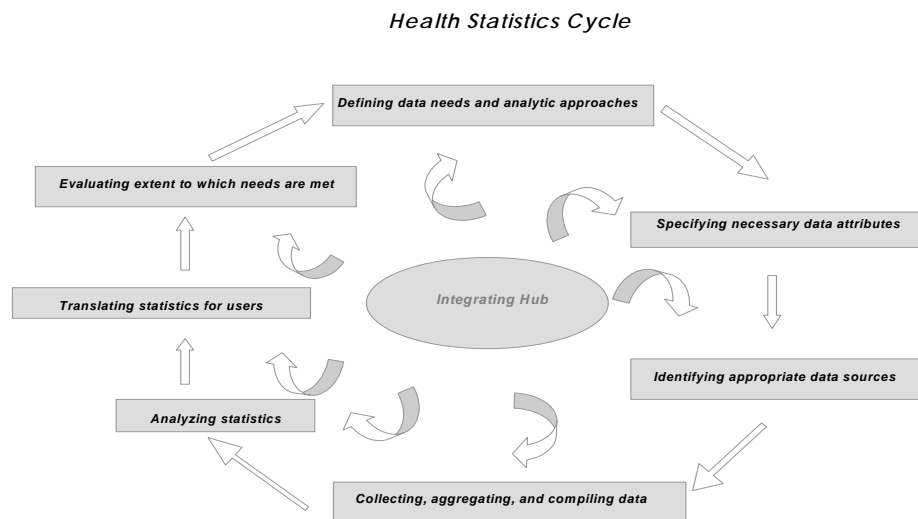
Health statistics, that is to say, the numerical data that characterize the health of a population and the factors that influence its health, are a cornerstone of the health system. When health statistics are timely, accurate, and relevant, they can provide critical data to assess the health of populations and to make best decisions about how to allocate resources and direct activities. A perennial challenge has been to improve the health information infrastructure sufficiently that the public's health can be measurably improved.

Presently, there are serious gaps both in the availability of data, and in the ability of current health statistics to meet needs of stakeholders. These gaps are worsened generally by a lack of overall coordination and integration, and by insufficient connections between producers of data and users of data. For example, researchers have long complained that information on vulnerable populations is scarce and of inconsistent quality. The same may be said of longitudinal and life-cycle data. There is too little information at sub-county and multi-county levels. Stakeholders face delays in getting access to data, and encounter obstacles in finding and using existing records.

Also a challenge is connecting new and emerging information needs to the capabilities of existing public health surveillance and data collection systems, many of which date from the nineteenth century. Presently, stakeholders are dependent on an overly complex and error-prone operation with (1) virtually no standardization across components (2) multiple systems performing the same tasks (3) essentially the same data stored in multiple systems (4) manual data entry into multiple systems, and (5) a large number of cumbersome data translations and interfaces, which combine to exacerbate problems with data integrity. To be sure, computerization of many of the traditional systems based mainly in county and state offices has improved tabulations of mortality and morbidity. The proliferation of data generation, storage and manipulation opportunities afforded by burgeoning information and communications technologies, however, has not been matched by systematic development of explicit procedures ensuring that relevant data is integrated and organized so that it can be useful. It is an irony of the Age of Computers that public health stakeholders can be rendered data rich but information poor.

Many factors influence the health of a population, and to be maximally useful, health statistics must provide a comprehensive and coherent picture of all health factors. Ideally, health statistics should encourage and reinforce a broad and integrated approach to improving health and reducing illness.

Overall, health statistics can be viewed as a cycle of actions addressed by an integrating hub (Department of Health and Human Services Data Council, 2002, p. 21) such as TDH's new Center for Health Statistics.



In order to support this integrating hub, a statewide system is needed that can (1) incorporate existing information from diverse sources (2) integrate demographic and health information with data on the economy, transportation, housing, education, the environment, social behaviors, and attitudes (3) accommodate new data collection needs (4) offer flexibility in the aggregation of the underlying data, and (5) enhance reports with visual representations of information based on common geographic references (Speer et al., 2002).

A system designed along these lines would facilitate study of health disparities and help with evaluations of quality of life. Such a system also would improve the targeting of interventions aimed at specific populations, such as efforts to reduce obesity among minority groups (Hoelscher, 2003). This system's approach would ensure that all relevant characteristics of population health, such as education in general and school

drop-out rates in particular, would not be ignored (Lleras-Muney 2001; Evans, Barer, Marmor, eds., 1994).

The “integrating hub” function for the Center for Health Statistics presupposes reliance on Internet-based geographic information systems (GIS) technology. Typified by the state-of-the-art approach being developed by the CDC’s Public Health Information Network (PHIN), the basic aim is the integration of health data. As described in a recent monograph, “PHIN will be a live, secure, Internet-based network for exchanging comparable critical health information between all levels of public health (local, state, and federal), and other critical information systems” (PHIN 2003). Web-based data networks, coupled with GIS systems, have significant implications for improving the effectiveness of health care services delivery and for better understanding the needs of vulnerable populations (Speer et al., 2002). It will be important for those working at the state level to partner with these national leaders in order to implement PHINs statewide. This process has already begun to take place in California (CalPHIN System, 2003).

There are other important advantages flowing from such a system and approach. The delicate balance between confidentiality and access is best maintained in an environment of consistent and comparable data. Benefits of early warnings cannot be overstated. As suggested by recent experience with the SARS epidemic, good public health practices can save lives as well as resources. With robust data collection and reporting systems in place, and with coordination engineered into routine practices, governments can respond quickly.

Texas departments, especially the health and human service agencies, need to be able to work together and with other constituencies, such as business and economic concerns. Grassroots participation is vital. With an expanded definition of health, agency workers need an expanded circle of experts with whom to collaborate in the implementation of steps necessary to achieve an improved data collection and reporting system. For example, demographers, epidemiologists, school specialists, labor union

representatives, corporate executives, as well as representatives from the natural environment and the cultural and political context should be involved in action plans.

Priorities for action correspond to gaps in the current system: the timeliness of the data, access to the data, and the geographic level of analysis. These gaps, and mitigating steps, invite consideration along a continuum:

- a. **Timeliness of Data:** This priority ranges from (1) data that could be analyzed within a very short period of time due to national threats such as bioterrorism events, to (2) data that sheds light on trends over time such as adolescent pregnancy rates, to (3) comparison of mortality rates by decade.
- b. **Level of Access:** The Access priority pertains to access by the general public to data that every citizen should be able to review, and to access of the raw data by research specialists. In addition to questions about who should access certain records, there are concerns raised by the means of access (e.g., data capable of being accessed electronically). Protocols for security and levels of access will need to be developed. Fairly consistent information exists for all 254 counties, but deeper pools of data exist for metropolitan areas and larger counties. A challenge is how best to nest the data so that all levels can be accommodated.
- c. **Geographic Level of Analysis:** The Geographic priority concerns data that should be available at the census tract level for local community planning and evaluation, as well as county-level data, and data that is appropriate to collect and report at the state level. Geographic presentation of the data facilitates multiple levels of aggregation, but GIS displays are only as good as the underlying data. Accuracy in addressing, especially in rural and isolated communities, needs to be encouraged.

The coordination of data and data resources constitute other urgent needs.

Collaborations should be built with other organizations and agencies to gain the best

possible data. This activity cannot and should not be exclusively TDH's responsibility. Broad-based efforts will be required to lower the barriers to sharing data between government agencies. One positive step toward cooperation and coordination would be implementation of a statewide Public Health Information Network (PHIN). The PHIN would provide an interactive, secure, Internet-based GIS system that would support the "... analysis of multiple data sets that can be turned into meaningful information. As with any network, the use of a common data language and interoperable architecture are keys to success" (PHIN, 2003).

To summarize, records management problems are complex, long-standing and deeply rooted throughout the public health system in Texas. Adequate and appropriate data to support day-to-day management and long-term policy decision-making are not currently available. A basic goal – ensuring that decisions are based on sound information – cannot be achieved without substantial and sustained efforts leading to modernization of current data collection and reporting systems.

III. Recommendations

In order to provide timely information and appropriate user education, the Goal 'L' Data Workgroup recommends the following:

- *Recommendation 1: Promote collaborative efforts with stakeholders and partners.*
- *Recommendation 2: Identify and evaluate significant statewide health-related data resources.*
- *Recommendation 3: Develop and implement standards for data collection, analysis and dissemination.*

Policy Statement:

Data-Driven Health Policy Saves Resources and Improves the Lives of Texans

Recommendations, Outcomes, Strategies, and Approaches:

Texas State Strategic Health Partnership, Preliminary Draft, August 15, 2003

1.1. Promote collaborative efforts with stakeholders and partners (Recommendation)

1.1.1. Continue the Data Workgroup (Partnership) as the State Health Data Advisory Group (ST) (Outcome)

1.1.2. Ensure the State Health Data Advisory Group appropriately reflects needed diversity and expertise (ST) (Outcome)

Establish a mechanism to recruit new sources of input and ensure continual participation from stakeholders/partners (Strategy)

2.1. Identify and evaluate significant statewide health-related data resources (Recommendation)

2.1.1. Complete inventory of all significant health-related data resources at state agencies (ST) (Outcome)

(web-based) identify, collect and evaluate specifics (based on CDC conceptual framework) – set criteria

2.1.2. Complete inventory of all significant health-related data resources at non-state entities (LT) (Outcome)

(web-based) identify, collect and evaluate specifics (based on CDC conceptual framework) – set criteria

2.1.3. Complete inventory of all significant health-related data resources at national entities (ST) (Outcome)

(web-based) identify, collect and evaluate specifics (based on CDC conceptual framework) – set criteria

3.1. Develop and implement standards for data collection, analysis and dissemination (Recommendation)

3.1.1. Establish and implement Data Standards Advisory Committee (ST/LT) (Outcome)

3.1.2. Research national and other state models/standards (ST/LT) (Approach)

3.1.3. Maximize public access to and understanding of relevant data (ST/LT)
(Outcome)

3.1.3.1. Presentation/Uniform Interface

3.1.4. Develop and provide guidance on methods that ensure privacy while maximizing
access to data (Outcome) (ST/LT)

3.2. Integrate and coordinate data sets (Recommendation)

3.2.1. Explore options of warehousing (and linkage of) state health-related data (ST)
(Outcome)

3.2.2. Implement warehousing (and linkage of) state health-related data opportunities
(LT) (Outcome)

3.3. Use GIS technology where appropriate (Recommendation)

3.3.1. Geocode all vital statistics data (ST) (Outcome)

3.3.2. Explore other health-related data sets that should be geocoded (ST) (Outcome)

3.3.3. Geocode other health-related data sets as appropriate (LT) (Outcome)

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